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President & CEO's Message

Dear Friends of HDSA,

With another year of COVID-19 looming over us, our Society has continued to learn, adjust and thrive. Despite disappointing HD research news earlier in the year and more events transitioned to virtual platforms, the HDSA Community has remained relentless in our approach to continue our mission to improve the lives of those with Huntington's disease and their families. With all the challenges we faced, we cannot thank our donors and loyal corporate partners enough for their amazing support.

In early 2021, we expanded **HDSA's Center of Excellence** program to a record 54 HD care teams with eight satellite sites across the country. We funded five research grants under the Society's largest research initiative, the **HDSA Huntington's Disease Human Biology Project**. We also awarded two **Berman-Topper Family HD Career Development Fellowships**, and two **Donald A. King Summer Research Fellowships**, a vital program to train the next-generation of scientists with research expertise in Huntington's disease. For a full breakdown of HD research from this past year, I encourage you to read ***The Marker: HDSA's 2021 Research Report*** which can be found at HDSA.org/marker21.

For the second straight year, we had to move the **Annual HDSA Convention** to a completely virtual

event and we welcomed thousands from across the globe. Thanks to the commitment of our speakers, exhibitors and sponsors, as well as the dedicated volunteers who once again ensured that the extraordinary magic of HDSA Conventions was preserved. Hopefully we will be able to bring the **37th Annual Convention** to Atlanta, Georgia in early June 2022 where we will feature an impressive hybrid program of in-person and virtual components.

Our extraordinary volunteers stepped up in the face of adversity to coordinate creative events that allowed folks to participate in HDSA's mission work in many ways. A prime example is the virtual **Seventh Annual Freeze HD event** held in October that raised more than \$212,000 and generated an enormous amount of awareness thanks to the amazing work of the Freeze HD Committee.

Aside from the events and fundraising initiatives, the power of storytelling helped HDSA generate more than **two billion** media impressions — the most ever! During a very 'loud' media year filled with political and health headlines, this meant that HDSA news and Huntington's disease stories reached more people than ever before to educate and motivate them in our work. The fight to continue to raise much-needed awareness continues to be an integral part in educating the world about HD.

One such major news story occurred in July when **Kala Booth** testified in front of Congress to encourage the passage of the **HD**

Parity Act. With our most comprehensive push yet to move this crucial bill forward, HDSA volunteers from across the country have come together to contact their local representatives and build momentum for this important bill.

From educational and fundraising events to advocacy and awareness, HDSA is able to provide help for today, hope for tomorrow for families affected by HD because of **you**. Your relentless commitment is ensuring help and hope, until we finally live in a world free of HD.

Thank you for your continued support!

With hope,



Louise Vetter

President & Chief Executive Officer



HDSA Centers of Excellence

HDSA Expands Centers of Excellence Program to 54 Clinics and Adds Eight Partner Sites

In February, HDSA announced that fifty-four outstanding Huntington's disease care facilities are being awarded the designation of HDSA Centers of Excellence for 2021. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to providing comprehensive care.

The strategic expansion of the HDSA Center of Excellence network allows expanded access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in Arizona, Arkansas, New Jersey, Mississippi, Ohio and South Carolina, HDSA now offers care locations in 35 States plus the District of Columbia. **In 2021, HDSA awarded \$1,750,000 to the Centers of Excellence network.**

The 2021 HDSA Centers of Excellence program expanded to 54 Centers from 50 in 2020, and from just 20 in 2015. The new HDSA Centers of Excellence are: **Barrow Neurological Institute** (Arizona), **Medical University of South Carolina** in Charleston, **Rowan University School of Medicine & Rutgers University RWJ Medical School** (NJ), **University of Arkansas**, **University of Cincinnati** (OH), and the **University of Mississippi Medical Center**.

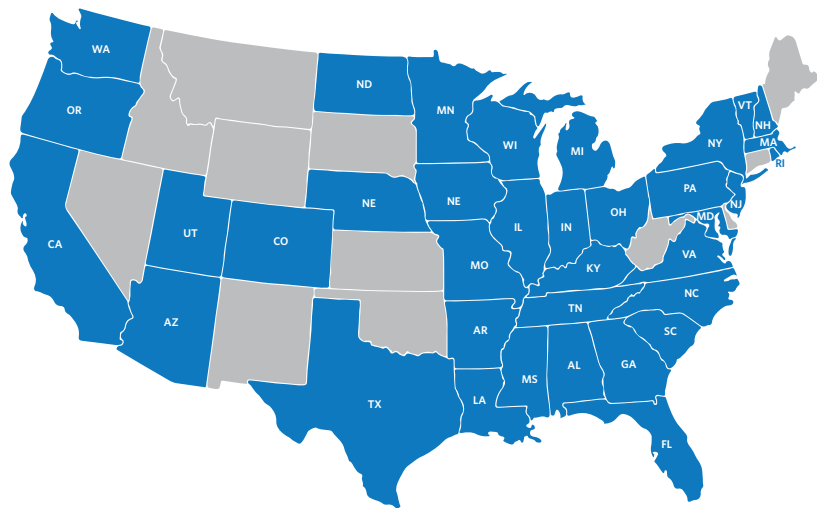
In addition, HDSA designated the **University of Texas Health Science Center at Houston, McGovern Medical School** as a new regional HDSA Center of Excellence because of their partnerships with **Covenant Medical Group Neurology** in Lubbock, Texas, **Texas Movement Disorders Specialists** in Georgetown, Texas and the **University of Texas Health San Antonio**. These new clinics will lower the burden on families and increase access to expert HD care throughout Texas and the surrounding areas. This brings the number of regional partner clinics to eight and the overall number of HDSA-supported clinics to 62.

"The expansion of the HDSA Centers of Excellence program ensures that more families affected by Huntington's disease have increased access to

expert and comprehensive care for this devastating rare brain disease," said **Dr. Victor Sung**, Chair of HDSA's National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham. "Additionally, clinical research conducted at many HDSA Centers of Excellence is vital to the development of potentially life-changing treatments to improve the lives of everyone affected by HD."

The HDSA Centers of Excellence provide an elite team approach to Huntington's disease care and research. Patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.

Louise Vetter, President & CEO of HDSA added, "HDSA Centers of Excellence share a common dedication to HD families. We are thankful to the clinical care teams who are able to provide incredible care with these modest awards and to the families whose generous support of HDSA's mission make these awards possible."





Huntington's Disease
Society of America

Centers of Excellence

HDSA Research Grants

2021 Human Biology Project Fellowships

In October of 2021, HDSA awarded five research grants under the Society's largest research initiative, the HDSA Huntington's Disease Human Biology Project.

Totaling more than \$728,000, these grants represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington's disease (HD) science in the human condition, instead of animal models, with direct participation of people affected by HD.

HDSA received impressive applications from researchers all around the world. After careful consideration by HDSA's Scientific Advisory Board, funds were ultimately granted to researchers from the United States, Canada, and Spain.

Ana Gámez-Valero, PhD

*Postdoctoral Research Scientist
University of Barcelona*

Plasma extracellular small RNAs as early biomarkers of Huntington's disease and indicators of dynamic changes in disease progression

Dr. Valero will analyze blood samples from pre-symptomatic and early-stage HD-carriers, as well as people without HD, to see if small pieces of the genetic recipe that creates mutant huntingtin protein, called small RNAs, can predict the onset of HD symptoms and how a patient responds to clinical interventions.



Tamara Maiuri, PhD

*Research Associate
McMaster University*

Poly ADP-ribose dysregulation in HD patient samples and potential for therapeutic intervention

Expanding upon a previous discovery that a step in the DNA-repair process called poly ADP-ribosylation involves huntingtin protein, Dr. Maiuri's project will explore whether pre-existing therapeutics may be useful to target this pathway for treatment of HD in cell models of HD.



Joan O’Keefe, PhD, PT

*Associate Professor
Rush University*

Neural underpinnings of cognitive, balance, and gait deficits in Huntington’s disease

Using cutting-edge brain imaging technologies, Dr. O’Keefe will investigate brain signaling patterns associated with cognitive and motor decline in Huntington’s disease as a tool for developing preventative and rehabilitative therapies.



Alby Richard, MD, PhD

*Assistant Professor and Neurologist
University of Montreal*

Oculomotor learning as a biomarker in Huntington’s disease patients

Dr. Richard will use noninvasive tracking techniques to measure changes in eye movements as a tool for rapid detection of subtle, early signs of motor and learning deficits in Huntington’s disease.



Charlene Smith-Geater, PhD

*Assistant Project Scientist
University of California, Irvine*

Modulation of E3 SUMO-ligase PIAS1 in 3D cortico-striatal assembloids and investigation of the HD-relevant CSF SUMO-ome

Using cell structures resembling brain tissue and HD-patient-derived CSF samples, Dr. Smith-Geater will test how reduction of PIAS-1, a protein whose activity is altered in HD, will affect the progression of HD.



2021 Donald A. King Summer Research Fellowships

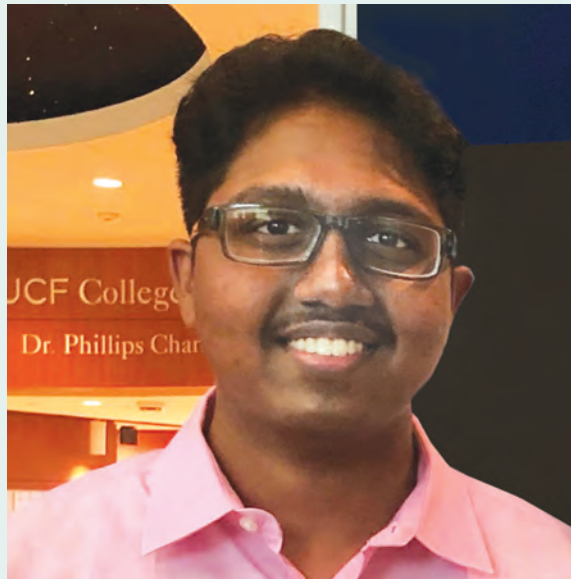
With the goal of attracting the next generation of bright young scientists to HD research and preparing them for the challenges of the field, HDSA established the Donald A. King Summer Research Fellowship in 2005 to support undergraduate researchers in their study of biological mechanisms underlying HD pathology. This program was established to honor Donald A. King, a tireless advocate for HD families who served as HDSA's Chairman of the Board from 1999 to 2003 before his sudden passing in 2004.

After careful review by HDSA's Scientific Advisory Board, two young scientists were awarded 2021 Donald A. King Summer Research Fellowships in April of this year.

Ratnesh Kesineni

University of Central Florida

Ratnesh was mentored by former HDSA Human Biology Fellow, **Dr. Amber Southwell**, to explore a potential link between biological age and aggregation of misfolded mutant huntingtin (mHTT) for potential therapeutic targeting.



Russell Wells

Whitworth College

Russell worked with **Michael Sardinia, PhD, DVM**, to study the effects of dihexa, a small molecule that has previously shown positive effects in Alzheimer's and Parkinson's disease models, for the treatment of Huntington's disease phenotypes in mice models.



2021 Berman-Topper Family HD Career Development Fellowships

With a shared goal of bolstering opportunities for young HD researchers and generous support from the Berman and Topper families, HDSA launched the **Berman-Topper HD Career Development Fellowship** in 2016 to support future generations of passionate HD scientists and clinicians. These prestigious fellowships provide \$80,000 of annual funding for three years to young scientists and clinicians who are motivated to make HD a focal point of their long-term career plans.

Since its inception in 2016, the program has supported seven emerging scientists in projects that have not only propelled them forward in their careers, but also made significant contributions to the HD research community. This year, after HDSA's Scientific Advisory Board carefully considered proposals from scientists across the globe, the Society was excited to name two 2021 Berman-Topper Fellows, **Dr. Eduardo Silva-Ramos** and **Dr. Adys Mendizabal**.

Under the mentorship of **Dr. Erich Wanker** at the Max Delbrück Center for Molecular Medicine, Dr. Silva-Ramos' project, ***"Characterization and targeting a novel HTT interacting E3 ligase protein complex,"*** will seek new insights into how the huntingtin protein is regulated in the body and what can be done to better target it for therapeutic development.

In her project entitled ***"HD epidemiology, healthcare utilization, and outcomes in racially and ethnically diverse populations in the US,"*** Dr. Mendizabal will study the actual prevalence of HD in racially diverse communities and how they utilize HD healthcare options. Dr. Mendizabal is the first clinician to be awarded the Berman-Topper fellowship and will be guided by **Dr. Yvette Bordelon** at The University of California, Los Angeles.



Dr. Adys Mendizabal



Dr. Eduardo Silva-Ramos

HDSA Center of Excellence Clinical Research Pilot Program

In 2021, HDSA awarded two grants under the **HDSA Center of Excellence Clinical Research Pilot Program**. These grants, totaling \$25,000, represent HDSA's patient-centric research focus by fostering novel clinical research projects within the HDSA Center of Excellence network. These pilot projects will unite scientists with HD families through their direct participation in clinical research.

Two clinical research pilot grants were awarded this year. The first to **Leonard Sokol, MD**, at Northwestern University, for a study on Meaning-Centered Psychotherapy for treatment of psychosocial symptoms and improved quality of life in persons with Huntington's Disease. The second went to **Deb Kegelmeyer, DPT**, at The Ohio State University. This study will evaluate whether telehealth is an effective medium to implement a 12-week movement to music program designed to enhance physical, cognitive, and psychosocial health in adults, as well as whether the intervention leads to changes in these domains.



Leonard Sokol, MD



Deb Kegelmeyer, DPT

2021 HDSA Highlights

Dr. Jeff Carroll & Dr. Beth Hoffman Join HDSA's National Board of Trustees

In December, HDSA announced that **Jeff Carroll, PhD** and **Beth Hoffman, PhD** were elected to the Society's National Board of Trustees.

"On behalf of HDSA's Board of Trustees, we are excited to welcome Dr. Carroll and Dr. Hoffman" said HDSA's President and CEO **Louise Vetter**. "They are both established scientific and volunteer leaders in the HD community whose experience will undoubtedly strengthen HDSA's mission work."



Jeff Carroll, PhD



Beth Hoffman, PhD

Dr. Carroll is an Associate Professor in the Behavioral Neuroscience Program and the Department of Psychology at Western Washington University. Dr. Carroll is co-founder of **HDBuzz.net** and continues to serve as the site's Editor-in-Chief. During his PhD, he trained with **Michael Hayden** (University of British Columbia), his postdoctoral studies were conducted under the supervision of **Marcy MacDonald** (MGH, Harvard Medical School). As well as conducting research, Dr. Carroll is a member of an HD family and carries the mutation which causes HD.

Dr. Hoffman is the Founder and CEO at **Origami Therapeutics, Inc.** At Origami, Dr. Hoffman is leveraging lessons learned during 20 years of CNS drug discovery to create a novel, precision medicine approach to treating neurodegenerative diseases by "fixing broken proteins". Dr. Hoffman served on the Board of Directors at HDSA's San Diego Chapter and currently serves on the Scientific Advisory Board of the Tau Consortium. Dr. Hoffman received an AB in Molecular Biology from Wellesley College, a PhD in Cell Biology from the Johns Hopkins University and was Chief of the Molecular Pharmacology Unit at the National Institute of Mental Health in Bethesda, Maryland.

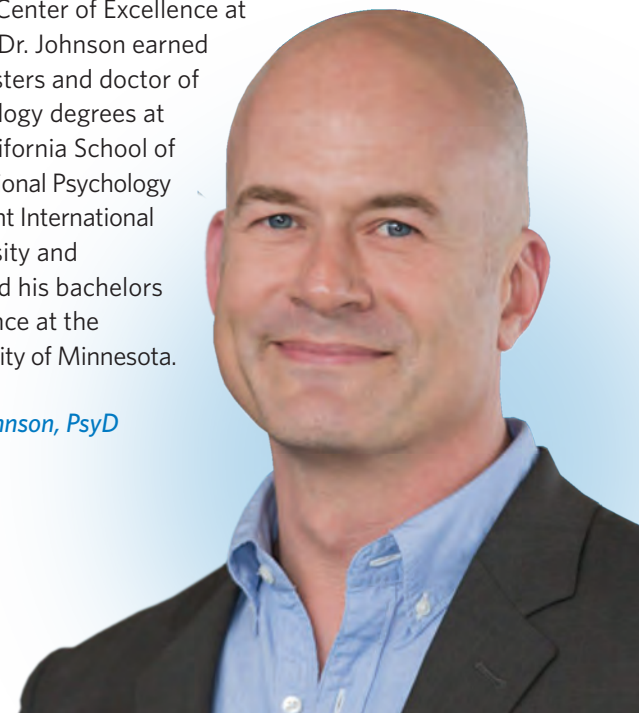
For more information about HDSA's National Board of Trustees, please visit www.HDSA.org/bot

HDSA Welcomes Dr. Arik Johnson as New Chief Mission Officer

Arik Johnson, PsyD has joined the Huntington's Disease Society of America this year as Chief Mission Officer. He is a licensed clinical psychologist who has spent more than 17 years caring for families affected by Huntington's disease (HD) and is highly respected leader in HD advocacy and care. A longtime member of the HDSA community, Dr. Johnson served on the HDSA Board of Trustees from 2010 to 2020 and was Chairman of the Board for the 2017-2018 term.

Most recently Dr. Johnson provided care at the Movement Disorder Program in the Department of Neurology at the University of California, Los Angeles (UCLA), as well as the HDSA Center of Excellence at UCLA. Dr. Johnson earned his masters and doctor of psychology degrees at the California School of Professional Psychology at Alliant International University and received his bachelors of science at the University of Minnesota.

Arik Johnson, PsyD



Scott Porter Invitational: HeroClix for Huntington's

ACTOR SCOTT PORTER PARTNERED WITH WIZKIDS AND HOSTED THE HEROCLIX FOR HUNTINGTON'S VIRTUAL EVENT IN MAY WHICH RAISED MORE THAN \$30,000 TO SUPPORT THE FIGHT AGAINST HD!

Scott Porter



Shine a Light on HD Hosted by Billy Harris

On December 11th, *Iron Chef America* judge **Billy Harris** hosted an interactive cooking experience with award winning chef, baker, and author **Nancy**

Silverton. Nancy answered questions and guided guests through preparing and plating the multi-course menu

from her award-winning restaurant in Los Angeles, Osteria Mozza. In addition, master mixologist, **Charlotte Voisey** made cocktails during this special virtual dinner party experience.



Nancy Silverton, Billy Harris and Charlotte Voisey



May Is HD Awareness Month — #LetsTalkAboutHD

May is **Huntington's Disease Awareness Month** and once again HDSA teamed up with members of the HD community to let the world know about this devastating brain disorder.

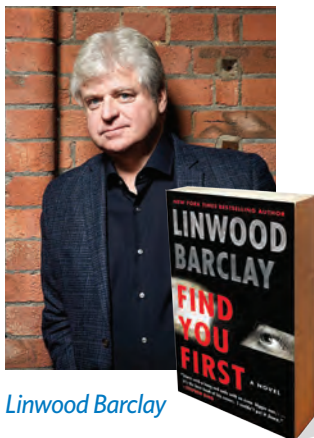
Ginny & Georgia Reunion Fundraiser

With help from HDSA's dear friend **Scott Porter**, the castmates and creators of the hit Netflix series, **Ginny & Georgia** participated in a virtual reunion fundraiser for HD. The much-anticipated event raised nearly \$5,000 and received more than 86,000 views on HDSA's YouTube channel.

TAKE THAT HD!

#LetsTalkAboutHD with Author Linwood Barclay

Acclaimed author **Linwood Barclay** released a new novel this year titled, *Find You First*, which features a character with HD. Linwood used his platform and shared a video supporting the fight against Huntington's disease.



Linwood Barclay

31 Days, 31 Stories

Sharing personal experiences is crucial in educating people about the impact HD has on individuals and families. Videos featuring members of the HD community sharing their narratives have been posted on HDSA's YouTube channel in HDSA's **31 Days, 31 Stories** series.



Athletes vs. HD

HDSA's first **Athletes vs. HD** online auction in May generated a ton of awareness in the sports world and raised more than \$2,600!



Lisa Jakub Hosts Yoga Event to Benefit HDSA

On August 21st, **Lisa Jakub** hosted a virtual yoga event that raised funds and awareness for HDSA in the fight against Huntington's disease. Lisa is a former child actor who starred in blockbuster films such as *Independence Day* and *Mrs. Doubtfire*. She is now an expert in yoga and guided meditation.

Lisa Jakub demonstrates a revolved crescent lunge yoga pose.



HDSA Founder's Day

On September 18, 1967, **Marjorie Guthrie** founded the **Committee to Combat Huntington's Disease** —



today's **Huntington's Disease Society of America**. We honor Marjorie's legacy to "do something" during the HDSA Founder's Day campaign. This year, the initiative raised more than \$32,866 to ensure that our social workers, support groups, education programs and critical HD research continue to help improve the lives those affected by HD.



HDSA Reintroduces HD Parity Act

On March 19th, the Huntington's Disease Society of America announced that **Senators Kirsten Gillibrand** (D-NY) and **Dr. Bill Cassidy** (R-LA), along with Representatives **Adam Kinzinger** (R-IL) and **Bill Pascrell, Jr** (D-NJ) have reintroduced the **Huntington's Disease Parity Act (S 868 / HR 2050)**. The HD Parity Act will waive the two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI). Medicare's two-year waiting period is particularly devastating for people with HD. Once a person with HD is deemed eligible for SSDI benefits, a process which can take years

even with Compassionate Allowance Listings, they are forced to wait two years to receive Medicare benefits. During the two-year wait, HD's destructive impact cognitively and physically robs the person of their ability to live independently.

Additionally, the genetic nature of the disease and its onset during prime working years has a tremendous financial impact on families with HD, forcing families to wait even five months to receive their financial benefit once they qualify for SSDI is too long.

"With the reintroduction of the HD Parity Act, we hope that Congress can work together to finally pass this bill that is so important to individuals and families suffering from Huntington's disease," said **Louise Vetter**, President and CEO of HDSA. "Like our friends in the ALS community, individuals with HD don't have time to wait to access SSDI benefits when they need them most. With the passage of HR 1407/ S 578 in 2020, we know that members of Congress understand the need to pass disease specific bills to fix disease specific problems."

In 2020, our friends in the ALS community saw a bill pass that provided a waiver of the remaining 5-month benefit waiting period for folks with ALS accessing Social Security Disability Insurance (SSDI) (HR 1407/ S 578). The bill, passed under unanimous consent, provides immediate access to benefits for folks with ALS, relief HD patients do not yet have but so badly



*Sen. Kirsten Gillibrand
(D-NY)*



*Sen. Bill Cassidy
(R-LA)*



*Rep. Adam Kinzinger
(R-IL)*



*Rep. Bill Pascrell, Jr
(D-NJ)*

need. Our friends in the ALS community needed this disease specific solution to a disease specific problem. Now, it's time for HD families to get the same. Like ALS, HD is a rare, fatal neurodegenerative disease that robs a person of their ability to walk, talk, and care for themselves. But unlike ALS, HD is genetic, and HD impacts a person's cognitive abilities and functions. HD families get no reprieve from this disease, generation after generation. And it's time HD families were exempt from these harmful waiting periods instituted into the SSDI program. Our families cannot afford to wait for help.

"The bottom line is that the HD Parity Act is a crucial bill that must be passed for Huntington's disease families," said Louise Vetter, President and CEO of HDSA. "Two years is too long for HD families and we need our representatives to step up and support this bill."

To learn more about the HD Parity Act, please visit [HDSA.org/takeaction](https://hdsa.org/takeaction).

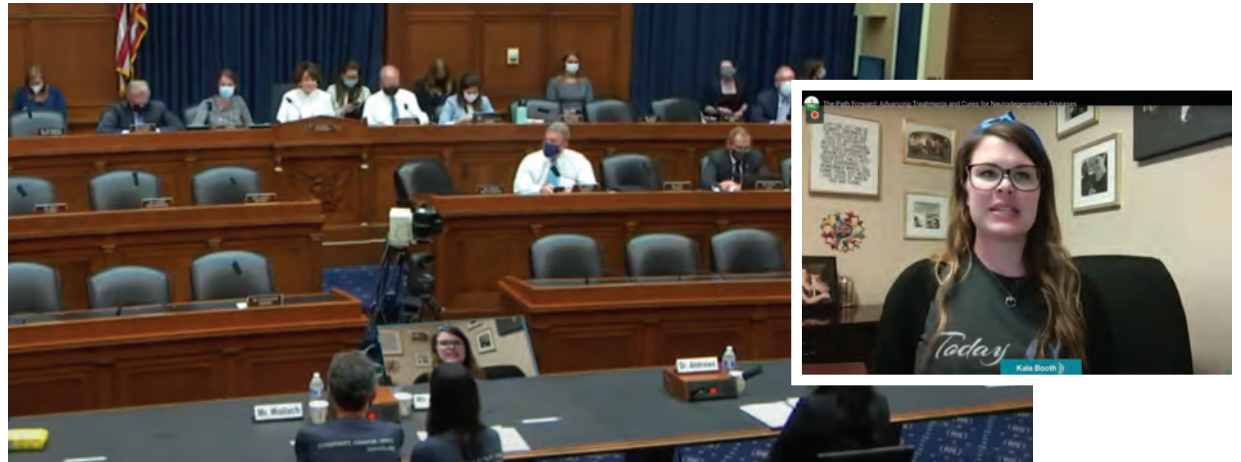
Kala Booth Testifies in Front of Congress

The Huntington's Disease Society of America (HDSA) applauded the House Energy and Commerce Subcommittee on Health for holding a vitally important hearing on July 29th that put a spotlight on Huntington's disease.

Kala Booth, an HD patient and caregiver, testified to the distinct challenges of living with HD, its multi-generational impact, and the importance of improving access to vital health benefits as outlined in the bipartisan **Huntington's Disease Parity Act (H.R. 2050, S. 868)**. The HD Parity Act will waive the two-year Medicare waiting period, as well as waive the five-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI).

"Even though Huntington's Disease is on the Social Security Administration's compassionate care list, HD families often spend years battling against an uninformed system that does not recognize or understand Huntington's Disease," says Booth in her written testimony. "This policy must be changed. Congress made an exception for patients with ALS and the same should be done for patients with HD."

"On behalf of families affected by Huntington's disease, HDSA is grateful for the Subcommittee's attention to advancing meaningful treatments for these neurodegenerative diseases," said **Louise Vetter**, President and CEO of the Huntington's Disease Society of America. "From the high cost



On July 29th, the House Energy and Commerce Subcommittee on Health heard the testimony given remotely by HD patient and caregiver, Kala Booth (inset) on the importance of the HD Parity Act.

of medicine to the scarcity of clinically relevant endpoints, HD families face overwhelming challenges accessing care. Passage of the HD Parity Act is something Congress can do right now to help families like Kala's."

"Huntington's is a dreadful disease that leaves a devastating impact," said **Rep. Bill Pascrell**. "The physical and emotional toll on victims and their families is enormous. They deserve all the support our government can provide them. Currently, the waiting periods for SSDI and Medicare coverage for Huntington's sufferers is a cruelly unnecessary gap. Rep. Kinzinger and I continue to push our bipartisan, bicameral fix to allow Huntington's sufferers to get their care faster. For Americans facing this difficult

diagnosis, we must make sure their lives as comfortable as possible."

"Individuals and families battling Huntington's disease face an overwhelming number of unimaginable challenges. It's critical that Congress ensures our policies make it easier for them to receive the care they need," said **Congressman Adam Kinzinger**. "I'm happy to see this Committee take a serious look at the barriers to care for individuals suffering with such horrible diseases like Huntington's disease, and I hope we can finally deliver the stability and certainty these families deserve by passing the HD Parity Act."

Watch Kala's testimony by visiting [HDSA.org/kala](https://hdsa.org/kala).

Simi Fehoko Wears HDSA Cleats During the NFL's #MyCauseMyCleats Campaign

Dallas Cowboy **Simi Fehoko** supported the fight against HD by wearing custom HDSA cleats during the NFL's **#MyCauseMyCleats Campaign** during a game against the New Orleans Saints on December 2nd. Simi, who comes from an HD family, paid tribute to his grandmother who passed away from HD. This marks the second time an NFL player wore cleats to raise awareness of HD. Aaron Donald of the Los Angeles Rams participated in the initiative in 2018. Thank you Simi! And congrats for the win over the Saints!

Simi Fehoko honored his late grandmother, Shelley Joette Jones (inset), by wearing custom HDSA cleats during a game on December 2nd.



- 1 Randell Hansen
- 2 MaryAnn Emerick
- 3 Paige Stafne
- 4 Andrew Bliss
- 5 Ken Nadsady
- 6 Samantha Cox



NYC Marathon Team Raises More Than \$64,000

Eighteen runners from across the United States participated in the 50th Anniversary running of the **TCS New York City Marathon** and helped raise more than \$64,000 to support the Huntington's Disease Society of America. **Randell Hansen** from California was the first member of "Team HDSA" to finish the 26.2 mile marathon in with an impressive time of 3:11:07. Randell has run 48 marathons in 48 states — just two shy of completing his goal of running 50 marathons in all 50 states.

"We can't thank our runners enough for all their hard work to not only fundraise, but also for their willingness to take on the NYC Marathon to support the fight against Huntington's disease," said HDSA's President and CEO **Louise Vetter**. "Each step they took through the five boroughs was a tribute to the

strength of the HD community and helped to raise awareness for this devastating, rare brain disease."

HDSA's Marathon Team included: **Jana Arkow** (New York), **Andrew Bliss** (Wisconsin), **Tom Brinkmann** (Missouri), **Keri Clark** (New York), **Austin Corbett** (Arizona), **Samantha Cox** (Illinois), **MaryAnn Emerick** (New York), **Randell Hansen** (California), **Ethan Kelly** (New York), **Jessica Marsolek** (Minnesota), **Ken Nadsady** (Ohio), **Gail Shurlow** (Michigan), **Jane Sommers** (Texas), **Paige Stafne** (Florida), **Ryan Struble** (New York), **Aaron Tellier** (New Jersey), **Laurie Travis** (Georgia) and **Erin Tubridy** (New York).

In addition to the generous donors supporting the HDSA runners, participation in the TCS New York City Marathon was made possible in part by sponsorship from **Eisner Amper LLC**.

#GivingTuesday

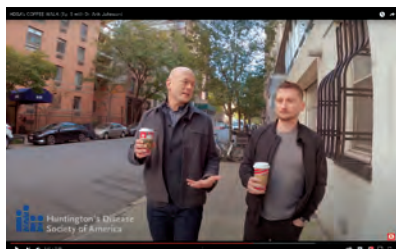
With more than 250 donations from around the world, more than \$99,000 was raised to support HDSA on Tuesday, November 30th, **#GivingTuesday** — a global day of giving. *This was the most funds raised for an HDSA Day of Giving ever!*



HDSA Coffee Walk

In November, **Chris Cosentino**, HDSA's Director of Marketing and Communications, hit the streets of New York City with HDSA's Chief Mission Officer **Dr. Arik Johnson, PsyD** and **Jennifer Simpson, LCSW**, HDSA's Assistant Director of Youth and Community Services where they discussed HD topics over a cup of coffee in the latest episodes of **HDSA's Coffee Walk** series.

Watch the series on HDSA's YouTube channel at [HDSA.org/coffeewalk](https://www.hdsa.org/coffeewalk).



Dr. Arik Johnson and Jennifer Simpson with Chris Cosentino in the latest episodes of HDSA's Coffee Walk.



HDSA Films

This year, HDSA produced four inspiring films featuring HD families. Watch them today on HDSA's YouTube Channel.

- 1 *The Dohertys: Finding the Funny*
- 2 *The Osborns: Our Legacy*
- 3 *My Father, My Hero*
- 4 *The Osborns*



William H. Macy Hosts Virtual Bourbon Tasting Event to Support HDSA

On June 17th, stage and screen star **William H. Macy** hosted a virtual bourbon tasting event to support HDSA which raised more than \$31,400!

William H. Macy



HDSA Partners With PatientsLikeMe®

The world's largest integrated community, health management, and real-world data platform **PatientsLikeMe (PLM)** announced on June 10th that it partnered with the Huntington's Disease Society of America to launch a virtual community for those living with Huntington's disease and for those caring for individuals living with HD. This tailored community will focus on education and peer-to-peer knowledge-sharing. This community will serve as a catalyst to expand researchers' knowledge of the condition through the analysis of patient-generated data. This collaboration will support patients and families grappling with HD and empower them to make their voices heard, learn from others who have faced the same experiences as them, and accelerate development of treatments and cures through participation in research. Through this partnership, PatientsLikeMe and The Huntington's Disease Society of America aspire to improve health outcomes and quality of life across the HD community. PatientsLikeMe's mission is to improve the lives of patients through new knowledge derived from shared real-world experience and outcomes. Huntington's Disease Society of America's mission is to improve the lives of everyone affected by Huntington's disease and their families.

"Partnering with PatientsLikeMe is an exciting new step in our work to help families affected by Huntington's disease come together to support one

another, find vital resources and share their journeys so that care for HD improves as quickly as possible," said **Louise Vetter**, President and CEO of the Huntington's Disease Society of America.

Brad Hornback, Lead Community Manager at PatientsLikeMe, remarked "We are thrilled to partner with the Huntington's Disease Society of America. PLM's vibrant community and robust health tracking tools will offer increased support to help individuals navigate their HD journey."

"This partnership is exciting in many ways, but the most exciting thing for us is that we get to continue our mission of elevating the patient voice to the level of evidence while bringing focus to Huntington's disease," said **Dr. Kate Burke**, Senior Medical



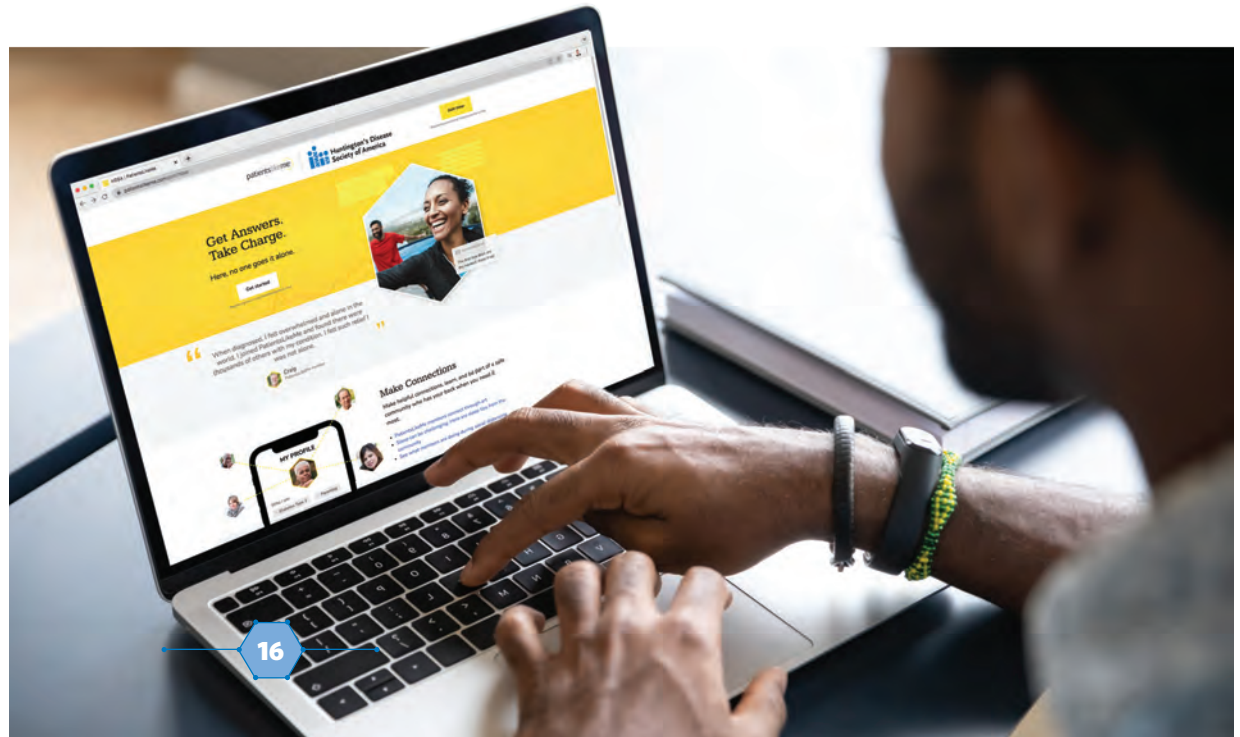
Brad Hornback



Dr. Kate Burke

Advisor for PatientsLikeMe. "As we involve more and more individuals in research and empower them to share their stories and experience with HD, we can help researchers discover new treatments and cures faster."

To access the platform, visit HDSA.org/PLM



HDSA Convention Welcomes Thousands from Around the World



Nearly 2,100 registrants from more than 33 countries participated in the **Virtual 36th Annual HDSA Convention** June 10th to 13th. The four-day virtual event featured

world-class presentations on the latest in Huntington's disease research and care. Despite not being able to meet in-person, the Virtual HDSA Convention allowed guests to connect virtually through the HDSA Convention app and visit the Virtual Exhibit Hall.

The HDSA Convention was kicked off by an inspiring keynote address from world-renowned speaker and best-selling author **Jon Gordon** who gave valuable tips on the power of positive thinking. In addition to the incredible workshops, attendees also enjoyed the NYA Talent Show, Back to the 80's Trivia & Costume Contest and the Closing Ceremony.

Sunday's Closing Ceremony featured HDSA's President and Chief Executive Officer **Louise Vetter** and **Dr. Victor Sung**, Chair of HDSA's National Board of Trustees, presenting national awards for outstanding service (*See list below*). In addition, the Closing Ceremony also featured the annual candle lighting ceremony in memory of those who have succumbed to HD.

With cautious optimism, it was announced that the 37th Annual HDSA Convention is being planned for Atlanta, GA on June 9-11, 2022.



Please check HDSA.org for 2022 Convention updates.

Thank you to our incredible sponsors, exhibitors and partners who helped make the Virtual 36th Annual HDSA Convention a success.

Recorded sessions from the Virtual 36th Annual HDSA Convention are available at www.HDSA.org/convention.

2021

HDSA NATIONAL AWARDS

PERSON OF THE YEAR AWARD

Yvonne Sweeten

MARJORIE GUTHRIE AWARD

E.J. Garner

WOODY GUTHRIE AWARD

Doug Schulte

YOUTH/JHD AWARD

Jenna & Gia Mannone

CHAPTER OF THE YEAR AWARD

HDSA Illinois Chapter

AFFILIATE OF THE YEAR AWARD

HDSA San Francisco Bay Area Affiliate

Thank You to Our Generous 2021 Convention Sponsors

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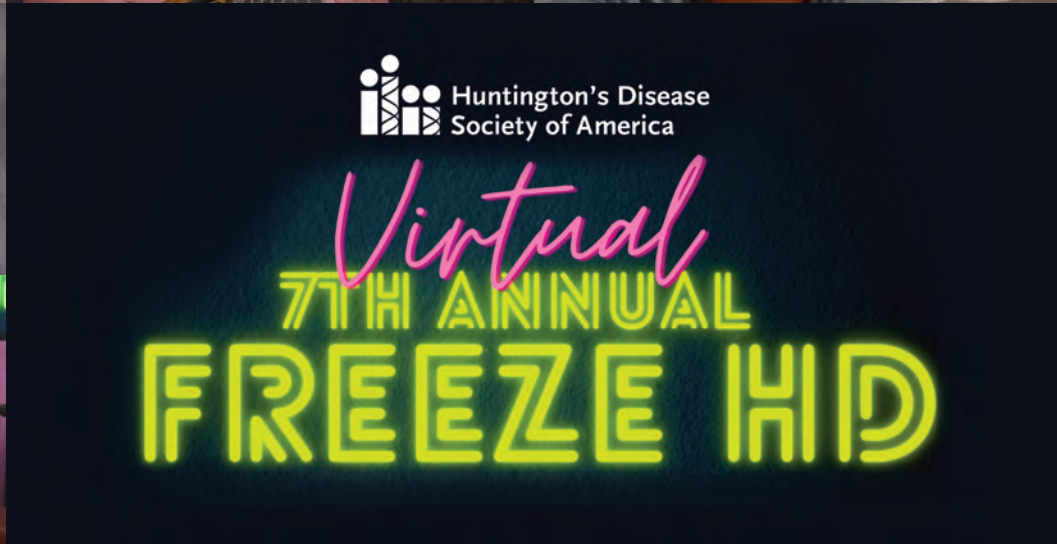


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Virtual Seventh Annual Freeze HD Raises More Than \$212,000

On Saturday, October 16th, the stars came out to support the Huntington's Disease Society of America at the **Seventh Annual Freeze HD** event. Hosted live from Los Angeles by **Kate Miner, Scott Porter** and **Jason Ritter**, more than \$212,000 was raised to support HDSA's mission to improve the lives of families affected by Huntington's disease, a rare, inherited brain disease.

The two and a half hour show featured appearances from **Marianna Palka, Basia Palka, Zach Gilford, Tom Ellis, Layla Alizada, Noel Fisher, India de Beaufort, Todd Grinnell, Bryce Dallas Howard, Paige Howard, Nora Guthrie, Wilson Bethel, Rachel Bilson, Brett Scallions, Jessica Etting, Dr. Victor Sung, Zibby Allen, Simon Helberg, Kimmy Gatewood, Brianne Howey, Patton Oswalt, Kelly Thiebaud, Briana Lane** and HDBuzz co-founders **Dr. Jeff Carroll** and **Dr. Ed Wild. Clare Dunn**, a cappella vocal group **The Edge Effect** and **Carly Ritter** provided incredible recorded music performances while **Miner** and **Brian Logan Dales** from **The Summer Set** performed live from the studio.

"Being virtual for the second straight year, allowed Freeze HD to share the story of HD families to a global audience while generating much-needed funds to support HDSA's support programs," said HDSA's President and CEO **Louise Vetter**. "It was a special night for HD families, and we are grateful to all who donated, sponsored, and performed and to

our incredible hosts Kate, Scott and Jason for putting together an amazing show."

The online auction featured 139 items that included memorabilia from the world of sports, music, video games, comic books, TV and movies, as well as celebrity Zoom calls, vacation packages and much more. The auction item with the highest winning bid was a Zoom call with signed items from the star of *'Lucifer'*, **Tom Ellis**, which went for \$14,300. The bidding for this item was so intense that Tom offered to do a *second* Zoom call for a total of \$28,600 for two winners!

Freeze HD was free to participate, and everyone was also able to purchase VIP After Party tickets to spend time with the hosts and other special guests on Zoom immediately following the program. Noel Fisher, Layla Alizada, Simon Helberg, Todd Grinnell, India de Beaufort, Briana Lane, Marianna Palka and others joined the After Party where guests participated in a trivia contest and won prizes.

Next year, Jason Ritter and the Ritter Family will serve as the Eighth Annual *Freeze HD* honorees. Along with Marianna Palka, the Ritter Family were co-founders of *Freeze HD* which has raised more than \$1,565,500 to support the fight against HD since its inception. HDSA hopes to bring *Freeze HD* back to an in-person event in Los Angeles. Stay tuned for more information regarding next year's event.

To learn more about Freeze HD, please visit [HDSA.org/freezehd](https://hdsa.org/freezehd).

Thank You!

THE SEVENTH ANNUAL FREEZE HD WAS GENEROUSLY SPONSORED BY THE FOLLOWING:

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Thank you to the Freeze HD committee for all their hard work and commitment to making Freeze HD a success:

Jessica Cain, Kipenzi Chidinma, Blake & Jenne Coler-Dark, David Cooper, Brian Logan Dales, Christopher & Lisa Davis, Jessica Etting, Matt & Courtney Hamilton, Gentile Koosed, Justin & Kate Miner, Marianna Palka, Scott & Kelsey Porter, Carly Ritter, Jason Ritter and Alana Yankowitz.

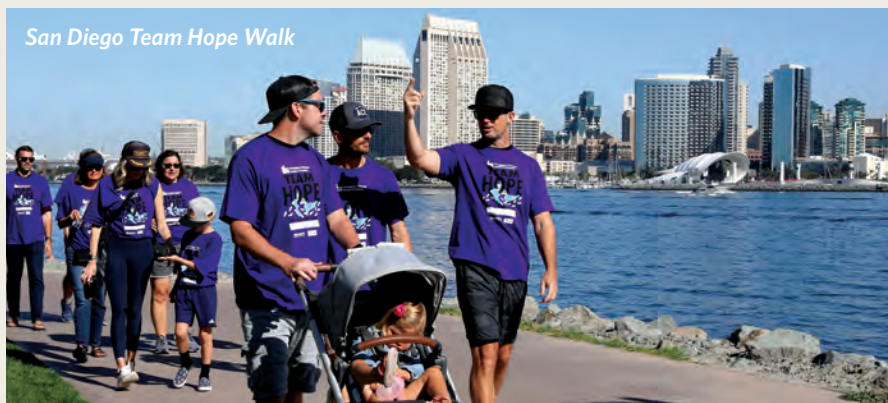
2021 HDSA Regional Events Highlights

Every year, HDSA's 50+ Chapters and Affiliates host more than 300 events across the country thanks to the amazing leadership of HD families & volunteers. Here are just a few!

PACIFIC WEST REGION

Arizona, California, Idaho, Montana, Nevada, Oregon, Utah, Washington, Wyoming, New Mexico, Colorado, Alaska

San Diego Team Hope Walk



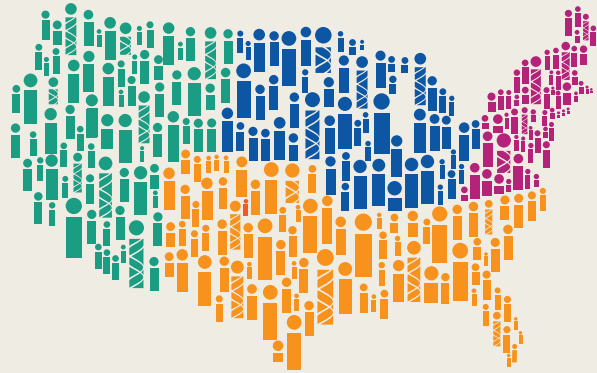
- **San Diego Team Hope Walk** / San Diego Chapter / \$77,500
- **Shine a Light on HD** / Los Angeles Chapter / \$65,000
- **Fairways for Hope** / Rocky Mountain Chapter / \$47,882
- **Washington Team Hope Walk** / Washington State Chapter / \$43,681
- **Los Angeles Team Hope Walk** / Los Angeles Chapter / \$33,958

UPPER GREAT LAKES REGION

Illinois, Indiana, Kentucky, Michigan, Missouri, Ohio, Wisconsin, Iowa, Minnesota, Nebraska, North Dakota, South Dakota

- **Bourbon, Bow Ties & Ballgowns, Celebration of Hope**
Northeast Ohio Chapter / \$211,392
- **Chicago Celebration of Hope** / Upper Great Lakes Region / \$103,219
- **Naperville Team Hope Walk** / Illinois Chapter / \$77,270
- **Team Run for HD, Chicago Marathon** / Upper Great Lakes Region / \$71,466
- **Cleveland Team Hope Walk** / Northeast Ohio Chapter / \$54,239





NORTHEAST REGION

*New York, New Jersey, Connecticut, Rhode Island, Massachusetts,
New Hampshire, Vermont, Maine, Pennsylvania, Delaware,
Maryland, West Virginia, Virginia, Washington DC*



New York City Team Hope Walk

- **New York City Team Hope Walk** / Greater NYC Chapter / \$112,728
- **Boston Team Hope Walk** / Massachusetts/Rhode Island Chapter / \$99,502
- **New England Celebration of Hope, Murder Mystery Night**
Northeast Region / \$88,000
- **Tewksbury Team Hope Walk** / Massachusetts/Rhode Island Chapter / \$41,170
- **Maine Affiliate Team Hope Walk** / Northeast Region Event / \$40,774

SOUTH REGION

*Arkansas, Louisiana, Mississippi, Kansas, Oklahoma, Texas,
Tennessee, North Carolina, South Carolina, Georgia, Alabama,
Florida*

- **Brittany's Hope for HD Golf Tournament** / South Region Event / \$38,440
- **Atlanta Team Hope Walk** / Georgia Chapter Event / \$35,491
- **Nashville Hope for HD Golf Tournament** / South Region Event / \$34,225
- **7th Annual Golf for a Cure** / Georgia Chapter Event / \$30,327
- **Greater North Texas Team Hope Walk** / Greater North Texas Affiliate / \$28,419

Brittany's Hope for HD
Golf Tournament



2021 HDSA Mission Reports

Advocacy

by Jennifer Simpson, LCSW

2021 was another year of socially distanced advocacy, but it didn't stop the HD community from making their voices heard in the halls of Congress. It was a year of unprecedented visibility for Huntington's disease and the HD community, with HD being highlighted in OpEds, Congressional hearings, and articles from our Congressional Champions calling for the passage of **HR 2050/S 868, the Huntington's Disease Parity Act**,

In March of 2021, the HD Parity Act, was reintroduced by in the House and Senate by our four champions, **Senators Kirsten Gillibrand** (D-NY) and **Bill Cassidy** (R-LA) and **Representatives Adam Kinzinger** (R-IL) and **Bill Pascrell, Jr** (D-NJ) (See article on page 12). After the introduction, HD community members got to work, writing, calling, and meeting with their Members of Congress to drum up support and cosponsors for our bill. HDSA launched the **HD Advocacy Caucus**, a now monthly meeting of HD community members who want to be more involved in advocacy, advocacy strategy, and recruitment of others in their lives to care and advocate for the HD community. With more than 100 members, the HD Advocacy Caucus has rallied 8 Senators and 76 Representatives to join as cosponsors of the HD Parity Act, with more to come in 2022.

As the year progressed, and COVID continued to derail plans for in person meetings, our community didn't miss a beat, continuing to take meetings over



Zoom with our members of Congress. Our community made the best of socially distanced advocacy, participating in a Congressional hearing virtually and also completing a **virtual "fly-in"** in October of 2021.



Kala Booth

In October, **Kala Booth** was afforded the incredible opportunity to highlight Huntington's disease in a hearing with the House Energy & Commerce Committee (See article on page 13). Kala, a young woman from Kentucky whose life has been and continues to be impacted by Huntington's disease, bravely shared her story with the Committee, and highlighted the need for the FDA to work with the HD community to find meaningful clinical trial endpoints, for Congress to work with the HD community to minimize barriers to quality long-term care, and demanded that Congress immediately pass the HD Parity Act. Her testimony was a watershed moment for the HD community, and we will continue to demand that HD be included in all Congressional discussions regarding neurodegenerative diseases.

After that incredible testimony, the HD community continued to advocate. We held virtual fly-ins on the

heels of Kala's testimony, capitalizing on the visibility Kala helped to create. Our community took 34 meetings in 3 days, focusing on members of the Senate Finance Committee and pushing hard for the HD community's needs to be recognized by Congress.

After these meetings, the HD community wasn't ready to rest. In November, members of the Advocacy Caucus spearheaded our **7 Days of Action** for the HD Parity Act, which saw more than 3,000 messages in support of the HD Parity Act sent to Members of Congress from 1,000 individuals across the country. This push from our community came right as our congressional champions jointly published an op-ed piece in **Roll Call**, a major Washington DC publication, calling on their colleagues in Congress to pass the HD Parity Act.

The work our community did in 2021 has laid the necessary groundwork we needed to bring us into 2022 ready to pass the HD Parity Act. We couldn't have gotten here without you, and we won't get over the finish line without your voice. If you have a new year's resolution in 2022, let it be to be an active advocate, and lend your voice to help our community pass the HD Parity Act.



JENNIFER SIMPSON, LCSW is HDSA's Assistant Director of Youth & Community Services. jsimpson@HDSA.org

Social Work

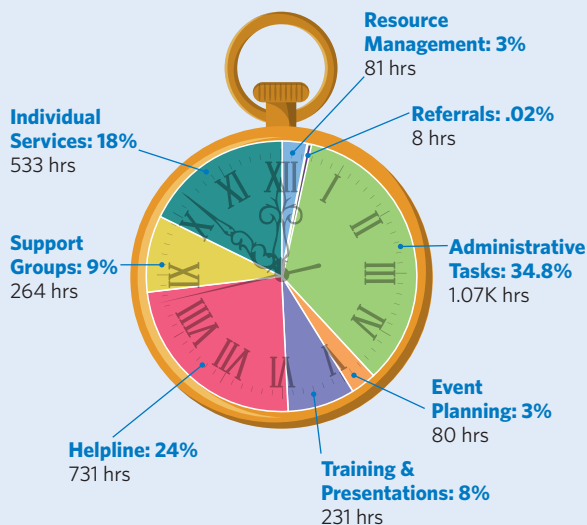
by Jennifer Simpson, LCSW

2021 saw big changes in our Social Work program. We said goodbye to several long serving social workers, and brought in new social workers who continue to breathe new life into their positions. We also launched **Social Solutions' Apricot Case Management Program** in July of 2021, allowing us to see in real time all of the incredible work of our chapter, affiliate and regional social workers across the country.

Between July and December of 2021, HDSA chapter and affiliate social workers took 731 hours of Helpline calls, held nearly 264 hours of support groups, provided 533 hours of individual services to families impacted by HD, attended and held 231 hours of

Hourly Breakdown of Social Work and Assistance by HDSA Chapters and Affiliates

(July-December 2021)



trainings and presentations, did nearly 80 hours of event planning, and more than 1,000 hours of administrative tasks, which include COE coordination, chapter and affiliate board meetings, resource organizing, chapter newsletter writing, grant writing and management, outreach to long term care facilities and more. As we continue to use the system, those categories are becoming more and more developed and our picture of the work of our social workers will become clearer and even more defined.

On the **National Helpline**, we also began tracking our calls in the *Apricot* system. 135 calls were logged to the National Helpline, totaling 2,260 minutes of assistance provided to the members of the HD community. We saw calls come in from across the country, with California, New York, and Texas providing the highest call volume. As many callers preferred to remain anonymous, several did not provide the state from which they were calling.

Helpline Calls by Location			
United States			
AL	3	MO	1
AZ	3	MT	1
AR	1	NE	1
1st CA	12	NV	1
CO	3	NH	4
CT	1	NJ	6
D.C.	1	2nd NY	11
FL	8	NC	4
GA	3	OH	7
IL	6	OK	4
IN	2	OR	1
KS	1	PA	8
KY	1	SC	1
LA	1	TN	4
MD	1	3rd TX	10
MI	2	VA	4
MN	1	WA	2
State not reported:		14	
International Call		Australia 1	

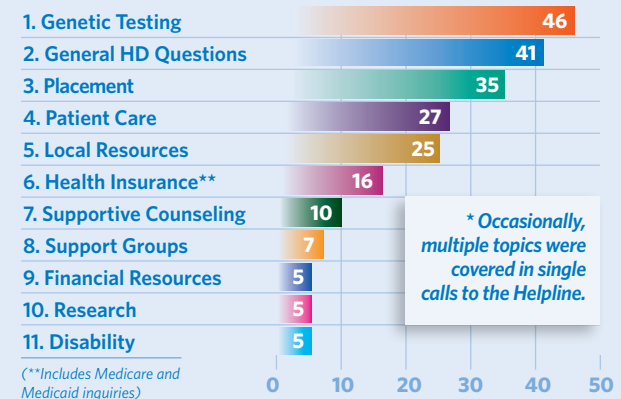
Number of National Helpline Calls By Location

(July-December 2021. Top three in bold.)

On the National Helpline, we continued to see particular issues come up again and again in calls from HD community members. HDSA continues to be a primary source for general HD information, as well as information on genetic testing for our community, as evidenced in the issues addressed in helpline calls. We also saw a high proportion of calls regarding placement for loved ones in long term care, skilled nursing or assisted living facilities for loved ones with HD. As we continue to use the *Apricot* system, we are likely to see some of these trends continue at the local level, and will be better equipped to break down the needs of our community from national and local perspectives.

Number of Topic Inquires Fielded on National Helpline Calls*

(July-December 2021)



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Education

by Debra Lovecky, MS

As we approach the end of the second year of our national health emergency, we continue to see the strength and resilience of the HD community and our HDSA volunteers. Despite state mandates that prevented in-person gatherings for much of the year, our chapter, regional and HDSA Center of Excellence social workers put considerable time and effort into creating educational opportunities for our families. From guest speakers at support groups, to weekly or monthly educational series, to virtual half day symposia, our event organizers used their creativity to bring novel programming to HD families across the United States. **In 2021, HDSA hosted 63, mostly virtual education days.** What a testament to the

commitment of our social workers and volunteers as well as our family viewers who tuned in regularly! Our sincerest thanks to all who made these virtual offerings possible.

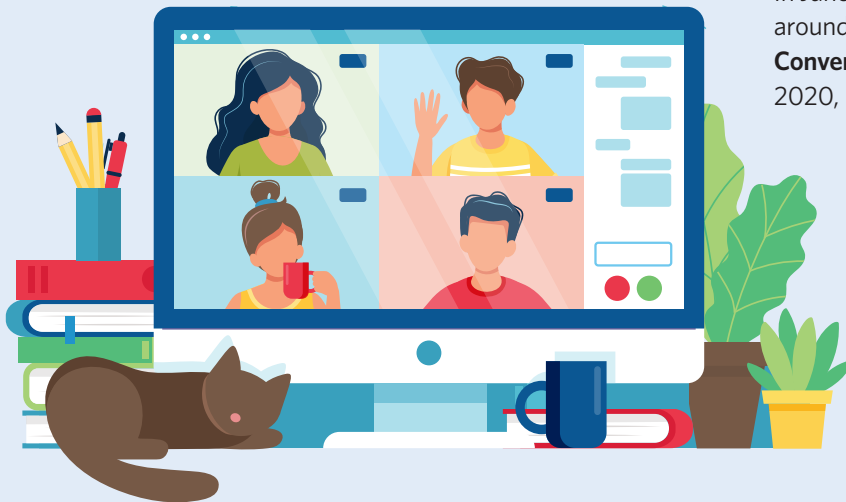
For a second year, HDSA also brought our HD families unique programming through **HDSA & Me**. Speakers included palliative care, physical therapy strategies, managing psychiatric symptoms, getting the most out of your telemedicine visit, strategies for managing HD along the continuum, and so much more. These webinars, as well as those offered in 2020, can all be found on HDSA's YouTube channel. Our thanks to our presenters who made these sessions fun and informative.

In June, HDSA welcomed family members from around the country to our second virtual **HDSA Convention**. Building on our experience from 2020, HDSA offered three days of dynamic programming in the areas of science/research, youth, young adults, caregivers, juvenile HD, positive/not symptomatic, early, middle and late stage HD, as well as two Spanish language sessions. The virtual Convention closed with our traditional national awards and candle lighting ceremony. You can read more about the HDSA Convention in this issue of *Year in Review* (See page 17).

During 2021, HDSA also formed a workgroup to create resources and materials for **a new long term care section on the national website (hdsa.org)**. This expanded section now offers a variety of materials for both families searching for long term care options for their loved one, as well as resources for care facilities and in-home care agencies.

In addition to family education, HDSA also continued to offer **free continuing education units** to occupational therapists and genetic counselors and a certificate program for physical therapists. In the second year of our partnership with the **National Society of Genetic Counselors**, we are pleased to report that 625 community based genetic counselors have completed the five module course. This is a remarkable achievement given we originally aimed for 600 completions by April 2023.

While in-person gatherings may remain a challenge in the coming year, HDSA is confident that we can continue to offer unique educational programming for our HD families and the professionals who work with them on any platform and in a variety of ways!



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Research

by Kelly Andrew, BS

2021 was a year of unprecedented challenges for HD research and immense fortitude from HD families. On top of ongoing difficulties from COVID-19, our community was rocked by the halt of the first phase 3 study for a huntingtin-lowering therapy, **Roche's GENERATION HD-1 trial**, which was quickly followed by the conclusion of **Wave's PRECISION trials**. But, as we mourned these losses, the strength of HD families and their unmatched commitment to clinical research set the tone for a year of scientific innovations to come.

The HD research pipeline has seen tremendous advances in 2021. **uniQure's** study of AMT-130, the first gene therapy investigated for HD, has successfully enrolled 19 participants in the US with additional recruitment underway. **Sage Therapeutics** has opened enrollment for a study of SAGE-718, an experimental drug to minimize early cognitive symptoms in HD. The first trials for orally-administered huntingtin-lowering therapies are imminent; **Novartis** has opened enrollment in Europe for VIBRANT-HD, a study of the fast-track designated drug, branaplam, and **PTC Therapeutics** will begin recruiting participants in a trial for PTC-518 in the new year. Neurocrine announced exciting results from KINECT-HD, its study of valbenazine, which offered strong indication that the drug reduced chorea in HD. **Prilenia** is studying the fast-track designated drug, pridopidine, in PROOF-HD, a trial

assessing its impact on functional capacity in HD. **Wave** has begun dosing patients in SELECT-HD, a study of a next-generation ASO to selectively lower mutant huntingtin protein, WVE-003.

While each of these clinical studies are causes for excitement, additional pharmaceutical players like **Spark**, **Triplet**, and **Ophidion** add hope to the pipeline with steadfast commitment to HD families and ongoing development of cutting-edge approaches to combat the disease. And, on top of industry approaches to fighting HD, researchers in the lab continue to innovate in search of new ways to stop HD. CRISPR gene editing approaches are evolving, huntingtin-lowering methods are being fine-tuned, and our scientific understanding of HD is growing thanks to community participation in observational studies like **Enroll-HD**, **HDClarity**, and **PREVENT-HD**.

Additionally, HDSA's dedication to research has grown stronger than ever.

In 2021, the Society granted nine fellowships to researchers in four different countries totaling over \$1.2 million. (See pages 4-7).

HD Trialfinder remains a force for fueling HD clinical trials with over 6,800 active users, and HDSA launched a new online community

with **PatientsLikeMe** to expand its ability to connect HD families with each other and reputable science. In a year of rapid and unpredictable change, HDSA has been inspired by the unwavering resilience and strength from researchers, clinicians, pharmaceutical industry partners, and, most importantly, HD families. We look forward to the endless possibilities that await in the new year.



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Disability Program

by Allison Bartlett, Esq.

Families, social workers, and medical professionals continue to benefit from the disability program. This year saw a broadening of the program from just Social Security disability to the disability process as a whole, including topics like short and long-term disability, health insurance, other private insurance, and legal and financial planning. The goal of the disability program is not only to help families navigate Social Security disability, but the disability process as a

whole. The earlier families start planning for the disability process, including legal and financial planning, the more protections and options they will have in the process.

There continue to be many ways to access disability information: the **HDSA website**, **Disability Tip of the Week** on Facebook, Instagram, and Twitter, and through the **Disability Chat Webinar Series**. All past

Disability Chats can be found on HDSA's YouTube page, and this year we covered a lot of important topics including, **Legal and Financial Planning for Late-Stage HD**, **How to Complete the Online Application**, **How to Complete the Online Appeal**, and **How to Follow-Up with Social Security**. To date, the *Disability Chat* webinars have 5,830 recorded views, making them one of the best resources for the HD community, families and social workers alike. In addition, I was honored to host a special *Disability Chat* for the **HDSA Centers of Excellence**.

Several new resources were created for families and social workers this year to help with the larger disability process. These resources include **disability, legal, and financial planning checklists**, and a **one-pager outlining how to follow-up with Social Security**.

I am available to answer your questions about Social Security disability, private disability, health insurance — Medicare, Medicaid — financial and legal planning, or the next steps in your disability journey. You can send questions to [HDSA.org/askallison](https://www.hdsa.org/askallison), phone me directly at (212) 242-1968, ext. 218 or email me at abartlett@hdsa.org

You can also learn more by visiting our website at [HDSA.org/disability](https://www.hdsa.org/disability).



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HDSA Support Services

by Arik Johnson, PsyD

2021 brought another year of challenges due to the ongoing COVID-19 pandemic. HDSA social workers and support group leaders rose to meet those challenges and assist people living with HD and their families. The **HDSA social worker network** is made up of over 70 individuals who work with HDSA Centers of Excellence, Chapters or Regions. The social worker is often the first point of contact for both clinical care and connection to the HDSA community. They address issues ranging from answering general questions about HD, to providing information about genetic testing, to dealing with specific HD symptoms, to talking about placement for a loved one. Helping people find other resources, local and national, is another important task and is met by having HDSA social workers positioned across the entire country. The **HDSA Youth Social Workers** offer additional support geared specifically to younger people living with HD. We greatly appreciate all that the HDSA social workers do for the HD community!

Support groups are a way that people living with HD have stayed connected in 2021. A support group is a place that people can talk with and learn from others' experiences, or to get emotional support from people who "get it." Many support groups continue to provide online meetings to minimize health risks, but also because it can be easier for people living with HD to participate if they don't have to leave home. While some groups are led by social workers, others are led by peer facilitators —

people who themselves live in an HD family. Most groups are based on location, but the shift to virtual can attract a wider audience. In fact, HDSA offers ten online only groups that are open to people from across the country. We all look forward to being able to meet in person again, and until that time HDSA support groups continue to provide a place for people living with HD to gather.

One more important resource for people living with HD is the **HDSA Helpline**. This service continues to be a way for people to get timely information from an HD experienced social worker. Whether they just

learned about HD in their family, or because they have a specific problem, Helpline callers can speak with someone who will listen to their story and help them find resources in the community. 2021 has shown us that regardless of what is happening in the world, the HDSA social workers and support groups network continues to work to improve the lives of people living with HD!



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Youth Programs

by MaryAnn Emerick

Going into 2021, we were full of hope and resilience. We thought nothing would stop us from seeing each other once again in person and making up for all of the many hugs lost. In order to ensure everyone's safety and facing many unknown challenges, the virtual platforms for events, youth programs and connecting with one another continued.

We added another **Youth Social Worker (YSW)** to our now team of five! The HDSA Youth Social Workers lead our **NYA Virtual Miniseries** that occur every other Saturday for one to two hours, keeping

young people in our community connected and supported while focusing on specific topics. Initially replacing our **NYA Youth Retreats** temporarily, we received so much positive feedback that these sessions needed to continue. These will continue in 2022, in addition to the anticipated return of our NYA Youth Retreats.

In order to find different ways to connect our community with our youth social workers, we created a way to receive direct support and education through our **"Ask a Youth Social Worker"** portal. Anyone can utilize, whether a young person in the community, a healthcare provider, a parent/guardian, or anyone that may have youth and young adult related questions or support.

Despite the difficult decision of the HDSA's Convention being virtual, we reached even more people within our community and were able to engage more youth and youth adults through **NYA Day** and our youth specific sessions. Many events in our community, found different ways to hold safe and successful hybrid events and realized this may be what we need to do moving forward. Although we cannot wait to see everyone, and all are pretty "zoomed out" these virtual experiences have helped provide support and resources to those unable to attend. We were

able to share our youth programs and supportive services at education days, support groups and other events around the country. During challenging times and hard news, we were able to conduct in prompt sessions for extra support as well.

Earlier this year, we announced our partnership with **HDYO** in launching the **HDSA Youth and Young Adult Mentorship Program**. The mentorship program is to support young people across the United States who face the everyday challenges of growing up in a family affected by HD and JHD. This will provide individuals (mentees) one-on-one time with another person in the community (mentors) that have received training and have ongoing support from our YSW team. The applications for mentors and mentees will remain open and we are excited for the future success of providing more support and connecting our community members.

On every platform, in every way we can, the NYA is determined to continue and find more ways to grow our youth programs in 2022. We will continue to have hope and resilience for all to come, remembering we are not alone and are stronger, together.

[Learn more at HDSA.org/NYA](https://www.hdsa.org/nyla)



MARYANN EMERICK is Manager of HDSA's Youth and Community Services.
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Together Again!



Join us on June 9-11, 2022 for the **37th Annual HDSA Convention** at the Marriott Marquis in Atlanta, Georgia! Following COVID-19 safety recommendations, we will be capping the number of in-person attendees and providing mandatory safety protocols. Since space is limited, be sure to register ASAP!

Can't make it to Atlanta? No problem! Every session

throughout the Convention will be livestreamed — **for free!** Our global audience will also have access to the HDSA Convention app for an interactive experience like no other.

To learn more about registration, scholarships, safety protocols, sponsorship and exhibitor information, please visit **[HDSA.org/convention](https://hdsa.org/convention)**.



Mission

To Improve the Lives of Everyone Affected by Huntington's Disease and Their Families.

Vision

A World Free of Huntington's Disease.

HDSA's Family of Services

Get the help you need from the comfort and safety of your home at no cost.

- **National Helpline:** (800)-345-HDSA (4372)
- **Online Support Groups:** HDSA.org/osg
- **Telehealth:** HDSA.org/telehealth
- **Disability Services:** HDSA.org/disability
- **Clinical Trial Participation:** HDtrialfinder.org
- **Locate Resources Near You:** HDSA.org/locateresources

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HDSA is an accredited non-profit with the highest ratings from the following national charity assessment organizations:



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